### Genetic Counseling Resources

### Associated with Comprehensive Sickle Cell & Hemoglobinopathy Centers

Sheila Neier, MS Children's Hospital and Medical Center Odessa Brown Children's Clinic 2101 E. Yesler Way Seattle. WA 98122

Message: (206) 987-7290

Appointment: (206) 987-7232 (Carol Flanagan)

Melanie Ito, MD, MS, CGC Columbia Health Center 4400 - 37th South **Seattle**, WA 98118 Phone: (206) 296-4650

Roger Fick, MS, CGC Mary Bridge Children's Hospital & Health Center P.O. Box 5299

**Tacoma**, WA 98415-0299 Phone: (253) 403-3476

### Prenatal Genetics Clinics

(For pregnant women only)

Kathleen Hayes, MS, CGC Julianna VonSchindell, MS Evergreen Hospital Maternal-Fetal Medicine 12040 NE 128th Street Kirkland, WA 98034 Phone: (425) 899-2200

Robert Resta, MS, CGC Amy Gonzales, MS Sandra Coe, MS, CGC Vicki Binns, MS, CGC Nancy Hsu, MS, CGC Deborah Dunne, MS, CGC Perinatal Medicine Swedish Medical Center 747 Broachway Seattle, WA 98122-4307

Phone: (206) 386-2101

Stefanie Uhrich, MS, CGC Leslie Carpenter, MS Linda Knight, MS Prenatal Genetics and Fetal Therapy University of Washington Box 356159 Seattle, WA 98195

**Seattle**, WA 98195 Phone: (206) 598-8130

Gail Hammer, MS, CGC
Obstetrix Medical Group of Washington, Inc. P.S.
314 Martin Luther King Jr. Way, Suite 402

**Tacoma**, WA 98405 Phone: (253) 552-1037

### **General Genetics Clinics**

Kathy Leppig, MD, MS, CGC Lael McAuliffe, MS, CGC Ute Ochs, MD Group Health Cooperative Group Health University Center 4225 Roosevelt Way NE Seattle, WA 98105 Phone: (206) 634-4036

Services limited to Group Health members

Robin Bennett, MS, CGC Whitney Neufeld-Kaiser, MS, CGC Corinne Smith, MS, CGC University of Washington Medical Center Medical Genetics, Box 357720 1959 NE Pacific Street Seattle, WA 98195-7720 Phone: (206) 616-2135

Justine Coppinger, MS, CGC Lael Hinds, MS, CGC Kathi Marymee, MS, CGC Inland Northwest Genetics Clinic 2607 Southeast Blvd #A100 **Spokane**, WA 99223 Phone: (509) 535-2278

Sarah Hall, MS
Madigan Army Medical Center
Developmental Pediatrics
Tacoma, WA 98431-5000
Phone: (253) 968-2310
Services limited to Armed Services personnel and their dependents

Pat Cooper, PhD, CGC Blue Mountain Genetic Counseling St. Mary Medical Center P.O. Box 1477 **Walla Walla**, WA 99362 Phone: (509) 525-1302

Susie Ball, MS, CGC Shelly Rudnick, MS, CGC Central Washington Genetics Program Yakima Valley Memorial Hospital 2811 Tieton Drive Yakima, WA 98902 Phone: (509) 575-8160

Genetics Program
Central Washington Hospital
1201 South Miller
Wenatchee, WA 98801
Phone: (509) 667-3350



# Hemoglobin E

**Trait** 

Information for parents about Hemoglobin E

### What is hemoglobin?

Hemoglobin is the part of blood that carries oxygen to all parts of the body. The usual type of hemoglobin is called hemoglobin A. Genes that we inherit from our parents determine what type of hemoglobin we have.

### What is hemoglobin E trait?

Hemoglobin E trait means that your child has inherited one gene for the usual hemoglobin (A) from one parent and one gene for hemoglobin E from the other parent. Hemoglobin E trait is not a disease and does not cause any serious health problems.

### What if a person has two hemoglobin E genes?

When a child inherits the gene for hemoglobin E from both parents rather than hemoglobin A, the child has homozygous (the same genes for) hemoglobin E. People with homozygous hemoglobin E have no serious health problems, but it may cause a mild anemia (low number of red blood cells).

## Why was my child tested for hemoglobin E?

The Newborn Screening Program screens all infants born in Washington State for certain disorders, including hemoglobin disorders. A small amount of blood was collected from your infant's heel and sent to the State Laboratory for testing. Other abnormal hemoglobin types are also detected.

# If hemoglobin E trait and homozygous hemoglobin E do not cause any health problems, why do I need to know that my child has it?

It is important to know about your child's hemoglobin E status because future children in your family, or other family members, may be at risk for having hemoglobin E-beta thalassemia, a serious disease described on the next page. People with hemoglobin E trait or homozygous hemoglobin E can pass the gene to their children.

### What is hemoglobin E-beta thalassemia?

Your child does not have hemoglobin E-beta thalassemia, but future children and other family members may be at risk for having it. When a person has hemoglobin E-beta thalassemia, they inherit one gene for hemoglobin E from one parent and one gene for "beta thalassemia" (low production of hemoglobin) from the other parent. These two genes together cause a life-threatening disease with no known universal cure. There are some therapies, like blood transfustions, that are necessary to help prevent complications, but hemoglobin E-beta thalassemia is a serious life-long disease requiring medical care.

### What do I do now?

We recommend that you and your partner have testing to determine your hemoglobin status. This would provide you with information on your chances of having a future child with hemoglobin E-beta thalassemia. To have this testing done, talk to your health care provider or one of the genetic counselors listed on the back of this pamphlet. You may also want to share this information with the rest of your family. They may be interested in finding out their hemoglobin status as well.

# What can I do if I have more questions?

If you have more questions, you can talk to your child's health care provider or you can contact the Newborn Screening Program using the information below.

Newborn Screening Program 1610 NE 150th Street Shoreline, WA 98155 Phone: (206) 361-2902

Email: NBS.Prog@doh.wa.gov Internet: www.doh.wa.gov/nbs

